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ABSTRACT

This paper summarizes the background, staffing, philosophy, participants, methods, and conclusions of the Case Studies on Facilitated Communication Project, which examined the use of facilitated communication (FC) with seven adult females, all with mental retardation and other disabilities. Information is provided on the development of the FC checklist, development of the Wisconsin Sensorimotor Pointing Assessment, and implementation of the FC intervention. The paper discusses the consequences to the project, staff, and participants when, under facilitated communication, allegations of sexual abuse were made against community service providers. Efforts to validate the authorship of facilitated communication and negative impacts experienced by project staff, family members, and participants are recounted. Some positive behavioral changes in participants are also reported. The project's major conclusion was that the risks involved in using FC when there is not objective evidence for the sole client authorship of messages overshadows any potential collateral benefits of FC (such as improvements in eye contact, initiations, or speech). The project identified a number of practices and philosophies that could be extracted from FC and used in non-FC therapy and training. Appendices provide additional detail on behavior tracking, a description of the FC checklist, and excerpts from facilitated messages. (Contains 10 references.) (DB)

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Description of Case Studies on Facilitated Communication

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Case Studies on Facilitated Communication

Project Description

Facilitated Communication (FC) is an augmentative communication interface technique with multiple components which has been the topic of much controversy (Cummins & Prior, 1992; Donnellan, Sabin, Majure, 1992). In FC, one person, a facilitator, provides physical and emotional support to another person, (the term client will be used in this paper to refer to the person with a disability) to "facilitate" typing or pointing to selections on a symbol display used for communication (Lehr, 1992). Those who are thought to benefit, are persons whose severe communication impairments are compounded by deficient hand function, possibly prohibiting a person from making independent selections from a symbol display (Biklen, 1990; Crossley, 1992a). One tentative purpose of FC is to teach the hand skills necessary to allow an individual to use an augmentative communication aide with increasing independence (Crossley & Remington-Gurney, 1992). As Cummins and Prior (1992) submitted, the use of augmentative communication devices to facilitate communication abilities for those with physical disabilities is not a new concept. However, in FC a high degree of physical assistance is added to these standard alternative and augmentative communication (AAC) practices. These descriptors of FC are hypothetical and the focus of much debate; fundamental to the controversy is the question of who generates the message when using FC (Calculator & Singer, 1992). The purpose of this paper is to provide a brief summary of the background, staffing, philosophy, participants, and methods of the Case Studies on Facilitated Communication Project (CSFC).

Historical Background

In June of 1992, the Wisconsin's Office of Developmental Disabilities and Department of Human Services contacted Dane County Human Services to determine if Dane County would be interested in conducting a demonstration project on behalf of the state on an approach called Facilitated Communication (FC). Dane County staff, in turn, contacted the Communication Development Program (CDP) - Trace Center to determine if there was an interest in participating in the proposed demonstration project.

As a result of diverse needs and concerns a resource group consisting of community service providers and clinicians was formed. This resource group was composed of Waisman Center and County administration staff, community service providers, a physician, a psychologist, and professors of Special Education and Communication Disorders from the University of Wisconsin - Madison. This group provided initial guidance on project design, suggested other individuals as resources, and served as a resource group to staff at the Trace Center who ultimately developed the project outline and determined project staffing needs.

Project Staff

Julie Gamradt, director of the Communication Development Program (CDP), provided management for the project. She also was the project speech and language clinician, responsible for analysis of communication abilities, development of the FC

checklist and many other documents used in the project. She also gathered data, consulted to community participants, and provided facilitation to clients. Ms. Gamradt is a speech-language pathologist (MS, CCC-SP) who has expertise in working with individuals who are not able to meet all of their communication needs through speech alone and in assisting such individuals, their families, and their service providers in developing an augmentative communication system to meet their needs.

Gregg Vanderheiden was the principal faculty sponsor and provided ongoing supervision to the project and the project staff. Dr. Vanderheiden, a Ph.D. in Technology in Communication Rehabilitation and Child Development, is the director of the Trace Center at the Waisman Center and is a professor in the Department of Industrial Engineering at the University of Wisconsin-Madison. Dr. Vanderheiden has been a leader in envisioning and developing the field of augmentative communication and has worked in this and other areas of technology and disabilities for over 20 years.

Ruth Huebner served as one of two occupational therapists . She was responsible for developing procedures for sensory and motor assessments, implementing these assessments, and analyzing the data obtained from pre and post assessments of sensorimotor capabilities. She also was responsible for compiling and writing portions of the documentation of this project. Ms. Huebner is a registered occupational therapist with a MS in rehabilitation psychology, and is currently a doctoral candidate in rehabilitation psychology. She is an associate lecturer in the Occupational Therapy program at UW-Madison and has expertise in the area of autism and sensory motor assessment.

Mary (Jamie) Klund was the other occupational therapist. She was responsible for assessing functional living skills, developing the FC checklist, providing facilitation to clients, gathering and analyzing data from caregivers and clients, providing consultation to community participants, and consulting with all members of the project team. Ms. Klund has an MS in occupational therapy with special training in augmentative communication, and many years of experience in a variety of rehabilitation and school settings. She is the occupational therapists in the CDP and Communication Aids and Systems Clinic (CASC) programs at Trace Center.

Paul White served as the behavioral specialist; he provided expertise in working with individuals with challenging behaviors. He identified significant behaviors for each client in the project, developed the procedures for tracking and analyzing behavior, and provided ongoing consultation to community care providers throughout the project. Mr. White has an MA in Educational Psychology. He has provided community intervention for people with developmental disabilities since 1975, and has worked through the Community TIES program since 1986. He is widely known for his expertise in developing behavioral interventions and facilitating adaptation to community living.

Cindy Strobel was the project assistant. She is a graduate students in Special Education with experience in working with people who have severe disabilities. She was responsible for much of the videotaping, weekly counts of behaviors for each client, and other data gathering and organization.

External Expert Input:

The services of three professionals with background in FC and recognized expertise in the area were utilized prior to the project.

Rosemary Crossley, from Australia, is considered by many as the originator of facilitated communication. She was invited to the Waisman Center in November, 1992. Rosemary provided guidance to the resource and project staff by clarifying her procedures for FC, and offering input on data gathering measures, project priorities, and other pertinent issues. Demonstration of the technique along with preliminary instruction were provided.

Dr. Steven Calculator (Professor of Communicative Disorders at the University of Delaware), who could be viewed as having a moderately skeptical attitude toward FC, met with project and resource group staff on January 28 and 29, 1993. Dr. Calculator was most helpful in designing the CSFC project. He provided guidance and consultation on implementation of the project, variables to track within the project, and data gathering and analysis procedures. Dr. Calculator has published extensively on issues related to the success, or lack of success, of FC-type strategies.

Project Philosophy

Any attempt to study the efficacy and effectiveness of FC is a challenging endeavor. Several issues and controversies guided the project rationale, design, and conceptual framework. These issues are:

1. FC is a controversial issue that can elicit strong emotional responses in individuals.

2. There is little definition of who would benefit from this approach.

3. The technique of FC is poorly defined and in fact is a multiple dimension intervention. Within this multiple dimension technique there are numerous components of FC.

4. There are a number of variables besides the actual components of the intervention which can effect intervention outcome.

    - Personal Historic Variables within individuals who use FC such as their behavioral, motoric, or medical characteristics, medications, life history, and trials with augmentative communication devices. Delineating these variables might help define who is likely to benefit from FC.

    - Intervention Variables include the physical equipment, display, positioning, types of tasks used in FC sessions and how often the FC is used.

    - Interpersonal Variables include: (a) the expectations of the facilitator; (b) the characteristics of the interaction between the facilitator and the client; (c) the quality of the caring relationship; (d) expectations about FC; (e) the alliance between the facilitator and the client; and (f) the

influence of the group of caregivers on both the client and the facilitator.

Because of these issues, the project staff committed to:

- trying to maintain an objective and neutral attitude toward FC (neither pro nor con);
- collecting detailed data on clients behavior, motor skills, and history before initiating the project;
- tracking the process of FC and the multiple components of FC throughout the project.

Because none of these variables were operationally defined, specifically assessed, or thoroughly described in the literature, project staff developed procedures and assessment instruments to analyze each of these components of FC. Specifically, an FC checklist was developed by CSFC project staff using modifications and expansion of a checklist from at the Adriana Foundation. This FC checklist was used to track intervention and interpersonal variables throughout the project. The Wisconsin Sensory Motor Pointing Assessment (WSPA) was devised as part of this project to assess sensory and motor capabilities. An overall behavioral tracking system was designed to establish a baseline and monitor challenging and adaptive behaviors throughout the project. For each individual, specific behaviors were defined and the frequency of these behaviors was monitored through on-site counting of behavior, checklists completed by care-providers and project staff, and occasional videotaping of clients. In addition, the OT FACT was used to monitor functional living skills. Pre- and Post-interviews with caregivers were completed.

Participants

Approval for the project was obtained through the Human Subjects Board at the University of Wisconsin-Madison. Appropriate release forms were included in the project. Individuals were nominated by project staff and case managers of the Department of Human Services of Dane County for inclusion in this project. From this list of nominated individuals, project staff and case managers chose seven individuals for inclusion in the project. Selection for the project was based on criteria developed from the literature, resource staff suggestions, and expert opinion. In addition, individuals who had a stable living and working situation, and who had a stable medical profile, were included.

Participant Profile Summaries

- All clients were perceived by nominating and CSFC staff as having receptive language and cognitive abilities that were stronger than expressive abilities;
- All clients were perceived to have a stable support group and staff that would be interested in following through on FC;
- All clients have had trials on a variety of alternative communication systems with successes below what their potentials were thought to be;

- Five client were described to have emotional difficulties suggestive of frustrated attempts to communicate;
- Five clients presented histories suggesting the presence of sensory or motor deficits;
- Four clients were described as having some ability to read or experience using some limited use of print within communication aids;
- Four clients were described as having difficulties with initiation;
- Three clients were described as having limited skills in communicating through sign language with absent or very limited verbal communication.
- Two clients were described as having strong independent living skills.
- All seven clients were female;
- All clients were employed in supported community vocational sites except one who was employed in a sheltered workshop;
- All clients were living in the community, usually in foster-care or in a group home. One client lives independently, with several hours of supervision each day.
- All client fell between the age range from 22 years, 1 month to 42 years, 8 months as of March 1, 1993. Average age was 31 years, 3 months;
- All clients had a diagnosis of mental retardation. Other diagnoses and incidence included: Peutz-Jahger Syndrome (1), Pradi-Willi Syndrome (1), Tuberous Sclerosis with left side hemiparesis (1), Current seizure disorder (3), history of seizure disorder without current seizures (1), impairment in left eye vision (1), unspecified neuromuscular disorder (1), arrested hydrocephalus (1), mention of cerebral palsy in history but not a current diagnosis (1), autistic-like disorder (1), mention of autistic disorder in history (2), and bipolar mood disorder (1). Other complicating diagnoses included: Scoliosis (1), myocardial ischemia (1), non-insulin diabetes mellitus, and arthritis (1);
- Six clients had information of previous intellectual assessment which included: IQ on the Leiter Scales - 38 and another client ranged from a 2 to 4 year equivalent. IQ of 35 (no test mentioned) Test of Auditory Comprehension of Language - 4 years, 1 month to 4 years, 5 months on two clients. Raven's Coloured Progressive Matrices - IQ 40 with reasoning ability in the 3-5 year range;
- All clients were reported to enjoy looking through books or magazines and/or being read to. All clients were reported to "seem to understand much of what is said" and two clients were reported to laugh at jokes. All clients were ambulatory, but two needed help on stairs or when walking long distances. All clients could feed themselves with utensils but three need help with cutting meat. All clients dressed themselves but three need help with fasteners. Five clients were able to do errands around the home independently and made at least occasional eye contact with their care-providers. Four clients made choices between objects and enjoy affectionate hugs;

- Four clients were reported to show self-abusive behavior, hypersensitivity to sensory stimuli such as noise or rough clothing, slow and impulsive behavior, and two clients were perceived as somewhat depressed by the care-providers;

- Four clients used 1-3 word phrases with poor intelligibility at an infrequent rate and all attempted to communicate with verbalizations that were either sounds or words. Two individuals communicated only with facial expression, body language, and sounds. Two individuals had between 150 - 300 signs that were used. One individual could write her name. All clients have had trials on a variety of alternative communication systems with minimal success;

- All clients were assessed using the Wisconsin Sensory Motor Performance Assessment. Some significant findings were:

    - None of the clients showed completely typical sensory and motor development;

    - All clients were able to point independently at least part of the time and were able to independently push keys on a keyboard or touch tone phone. Five of the seven clients could independently and accurately push specific keys marked with a green dot when asked;

    - All clients demonstrated a moderate to severe variance from typical performancein the area of visual tracking. Four clients showed a severe variance from typical performance in visual tracking;

    - All clients demonstrated a moderate to severe variance from typical performance in motor planning; however, this finding is confounded by the potential of less than typical performance in the area of cognition among clients;

    - Six of seven clients showed scapular winging with shoulder girdle instability, limitations in eye contact, involuntary motions such as athetosis or dyskinesia, speech dysprosody with a deep monotonic voice, abnormalities in facial expression ranging from a flat face to dyskinesia, and perseveration on tasks that could be redirected;

    - Five of seven showed very poor endurance, inconsistent and/or unstable finger pointing ability, or mild hypersensitivity to touch pressure (or movement by another);

    - Four of seven showed inadequately-established hand preference, abnormalities in finger posturing, synkinesis (associated movements) in the fingers, abnormalities in initiation or speed of movement, arousal deficits, or mild abnormalities in processing auditory sensation;

Method

Following the selection and consent processes, the participants began pre-assessment procedures to determine a baseline of performance. A "staggered start" approach was used with one or two different participants beginning the assessment procedure each week over the course of five weeks. All assessments were conducted

within community settings (in family homes, work sites, client residences, etc.). One or more of the client's family members or other service providers (as authorized by the guardian) observed each assessment.

The FC training technique was introduced to participants following baseline using a "staggered start" approach over five weeks. During two introductory sessions the expert facilitator trained those who were responsible for providing continuation of FC, determined optimal physical support, and provided information to all regarding the techniques of FC. The two training session were conducted on different days and videotaped. Additional information was gained through retrospective interview of the expert facilitator; the expert also completed an FC checklist.

The intervention phase lasted approximately six months for each participant. During this phase the following project activities occurred:

(a) On-site use of the recommended FC training technique: Service providers were asked to use the FC technique on a daily basis for approximately 45-60 minute sessions. However, compliance with this request was low.

(b)Weekly on-site visits by a member of the project team to update FC procedures, to provide and study FC intervention, addressing behavioral or other concerns, and gathering data using the FC checklist. See Appendix A for a more specific description of the checklist used.

(c) Monitoring of Behavior: In some cases daily rating sheets were used. Biweekly on-site counting of behavior was performed by the project staff. See Appendix B for a summary of the behaviors tracked for clients.

(e) Periodic videotaping of intervention sessions:

Following the six-month intervention, post-testing and exit interviews were performed. A plan was developed to transition each client out of project services and into on-going services to provide some continuity of care.

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Summary and Conclusions from Case Studies on Facilitated Communication

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Case Studies On Facilitated Communication

Project Summary and Conclusions

Background & Philosophy

The Case Studies on Facilitated Communication (CSFC) project was undertaken by the Trace Center at the Waisman Center in response to a request from state and county agencies providing services to individuals with disabilities (Wisconsin's Office of Developmental Disabilities and Department of Human Services, Dane County Department of Human Services). The purpose of the project was to explore the experimental technique referred to as facilitated communication (FC).

One focus of the project was to clarify the nature and process of FC by identifying specific clinical practices and strategies associated with it. From early on in the project, it was recognized that the techniques or practices referred to as facilitated communication were poorly defined in the literature; only philosophical and general guidelines were available (e.g., DEAL, 1992; Lehr, 1992). It was also observed that FC was not a single technique nor even a curriculum-like intervention; rather FC was a complex blending of many interventions, and a philosophy of interacting with those having severe disabilities.

A second focus was to examine some of the potential effects of FC. The need for FC and changes occurring with FC have been described in the literature in the areas of communication (e.g., Biklen, 1993), sensorimotor abilities (e.g., Biklen, 1990; Crossley & Remington-Gurney, 1992), behavior (e.g., Crossley, 1992; Donnellan, Sabin, & Majure, 1992), and independent living skills (Strandt-Conroy & Sabin, 1993). Because none of the reported needs and changes were operationally defined, specifically assessed, nor thoroughly described in the literature, project staff developed procedures and assessment instruments to analyze each of these variables.

Despite controversy associated with FC, project staff were committed to maintaining a non-biased philosophy during the course of the project. This philosophy was perceived as necessary to objectively observe the use and effects of FC.

Methods

Current literature pertaining to FC was reviewed prior to starting the project and the literature review continued throughout the project. This literature review was used to identify critical FC issues, contributed to project design, and was utilized by project staff as educational tools for community personnel. In addition, project staff consulted with individuals recognized to be national and international authorities in the area of FC as a part of the project development process. On-site consultation to project staff was obtained from Rosemary Crossley of Australia, and Dr. Stephen Calculator of the University of Delaware.

Seven adult woman were selected for participation in the project. These individuals were felt to have stronger receptive than expressive language skills. All seven had a severe

communication impairment and a diagnosis of mental retardation. None of the individuals showed completely typical sensory motor development. The augmentative communication systems tried with the participants in the past were viewed as inadequate for meeting their communication needs.

A professional educational consultant was hired to introduce FC to the participants. This consultant was an experienced practitioner of FC who had used FC with over fifty individuals in a two and a half year period. She was considered by many proponents of FC on a state and national level to be an "expert" facilitator. She participated in the first two FC sessions for each participant, but did not continue to provide FC after these two session. Within these two initial sessions the FC consultant provided training on the use of FC to family members, service providers and project staff. Following these two initial sessions, project staff continued to work with community facilitators in the provision of FC.

A number of evaluation and monitoring procedures were used to establish base line and track changes in sensorimotor performance, behavior, independent living skills and communication during the conduct of the project.

Pre-assessment Procedures:

a. The Wisconsin Sensorimotor Pointing Assessment (WSPA), devised as a part of this project, was used to assess sensory and motor capabilities. Specific components of the participants' ability to point and access a keyboard were assessed.

b. Counts and ratings of adaptive and challenging behaviors were completed for all participants by project staff and some service providers. A list of critical behaviors for each participant was developed based on observations, questionnaires, and interviews with family members and service providers. Some of the specific behaviors assessed pertained to communication (e.g., ratings of appropriate conversation). See Appendix A for a list of behaviors that were tracked across participants.

c. The OT FACT, a structured interview assessment using a computerized rating system, was completed based on the reports of independent living skills provided by service providers and family members. This assessment of functional living skills was considered a measure of `quality of life'.

d. Interviews with service providers and family members were conducted to collect information on the past and current status of behavior, communication, independent living skills, and sensorimotor performance of each participant.

Introduction to FC

All seven individuals were introduced to FC by the experienced FC practitioner in two sessions. The experienced FC practitioner introduced FC to all participants within the context of set work. The set work used was structured practice activities, primarily made up of tasks such as yes/no or fill in the blank questions. The answers to the practice materials were assumed to be predictable by both the participant and the facilitator. The predictability of answers to both the participant and facilitator was viewed as critical because it was within the context of set work that the facilitator was to learn how to

correctly facilitate with the participant. The experienced FC practitioner also used set work as a means of inferring participants' reading, writing, language or other skill levels. She viewed the output facilitated in response to set work questions as a valid indication of the participant's skills and preferences. The experienced FC practitioner noted that FC was to be used in progressively more unstructured and open ended conversational activities (less predictable) once intelligible output was facilitated within set work.

Intervention and On-Going Data Collection:

The intervention phase lasted approximately six months for each participant. During this phase the following project activities were carried out:

a. On-site use of the recommended FC techniques: Service providers were asked to use the FC technique on a daily basis for approximately 45-60 minute sessions. Compliance with this request was generally low.

b. Weekly on-site visits by a member of the project team to update FC procedures, to follow along and study FC intervention, addressing behavioral or other concerns, and gathering data using the FC checklist. See Appendix B for a more specific description of the checklist used.

c. Monitoring of Behavior: In some cases daily count and rating sheets were used by service providers or family members. Biweekly on-site counting of behavior was performed by the project staff. See Appendix A for a summary of the behaviors tracked for clients.

e. Periodic videotaping of intervention sessions.

Following the six-month intervention, post-testing and exit interviews were performed. A plan was developed to transition each client out of project services and into on-going services to provide some continuity of care.

Results

Use of FC by Experienced FC Practitioner

Although the experienced FC practitioner started out using set work in as structured format with each participant, she progressed to using FC to converse with participants within the first two sessions. She viewed that the output produced in conjunction with FC was valid communications of the participants. In this way FC was assumed to be a means of communicating with the participants.. The facilitated output during these first two sessions for five of the seven participants was characterized by full sentences with few spelling errors. The content of messages often suggested a desire to keep using FC, at times presenting some introspective thoughts on their disability, and expressions of gratitude toward the experienced FC practitioner (see Appendix C). The output for the remaining two participants was less extensive and sophisticated. However, a limited number of full sentences were produced by these two individuals as well. The sophisticated output across clients was viewed by the experienced FC practitioner and others who participated in the training session as evidence of higher cognitive, linguistic and literacy skills than previously suspected.

Withdrawal of One Participant

One participant was withdrawn from the project by her mother during the first several weeks. Her mother had experienced emotional distress and disbelief following the facilitation of sophisticated output when the experienced FC practitioner introduced FC to her daughter. Her disbelief in the suggestion that her daughter had significantly higher level skills than anticipated ultimately lead to pulling her daughter out of the project.

Use of FC for Communicating With Two Participants

For two of the remaining six participants, community facilitators progressed from using FC within set work to using it within conversation during the course of the project. Like the experienced FC practitioner, the community facilitators viewed facilitated output as being the valid communication of the participants and reliable indicators of their skill levels. For one participant, the change from using FC within structured set work to unstructured conversations occurred within the first two to three weeks of the project. For the second participant, this change occurred during the last two months of the project.

In both situations where the use of FC progressed from set work to conversational use, allegations of sexual abuse and misconduct against community service providers occurred in conjunction with FC. The allegations occurred within the first three weeks of the project for one participant and within the last two months of the project for the other participant. The allegations were against service providers who worked with the participants. The events which followed dominated the remaining course of the project for these individuals, ultimately over-shadowing any other impacts of the intervention.

Following the allegations, there was a demand for validation testing to determine the authorship of messages produced with FC by these participants. No one was available locally with knowledge or experience with such validation testing. Portions of the pre-published validation procedures developed by Dr. Stephen Calculator of the University of Delaware were completed with one participant by local therapists. These procedures were viewed as controversial by many proponents of FC. The assessment procedures included a variety of highly structured and controlled language tasks (e.g., picture identification and object description tasks) using a variety of modalities as input to the participant (e.g., presented material auditorally, tactually, visually). The facilitator who provided FC during the allegation was involved in the testing. During portions of the activities the facilitator was aware of the question or task being presented to the participant while in other portions they were naive to the specific questions or tasks being presented. A comparison was made between the participant's performance on tasks within these two conditions.

The report generated as a result of this testing stated that "...there was limited evidence that [participant 1] was communicating in a reliable way using facilitated communication..." The examiners reported that correct responses occurred only when the facilitators had knowledge of the stimulus. They further reported that there was "insufficient clear evidence" to indicate authorship of messages originating from the facilitators involved in the testing.

Formal validation testing was not completed with the second participant. The abuse investigation was halted after a few days when in conjunction with a different facilitator (another vocational service provider) "IFIB" was typed. This was assumed to be a retraction of the initial allegation. Later, informal validity procedures were completed by

her vocational and residential staff. No evidence of reliable communication was found within these procedures.

The impacts of the controversy resulting from the allegations and subsequent questioning of authorship had a serious and long lasting impact on a number of the project participants, their service providers, and family members. In one case, the job coach who facilitated during the allegations was later fired for unethical conduct after the test results failed to support the contention of valid communication. In the second case, the participant's residential service provider, devastated by the accusation that had been made against her (in spite of the retraction), ultimately took a different position with her employer, in effect ending the long term and close relationship with the participant. At the onset of the project this participant's guardian had described the residential provider as "the best thing that had ever happened to her" (the participant). This had also been the consensus of her community team. As a result, most individuals on the community teams viewed the events as detrimental to the participant and ultimately took steps to eliminate or significantly restrict the use of FC with her. The guardian of the participant also viewed FC as a serious threat to the participant's quality of life following the events that unfolded after the allegation (the guardian was not involved in the allegation).

Use of FC Within Set Work for Four Participants

The facilitators of the four remaining participants continued to use FC-like interventions, for the most part, within structured, set work activities. These activities were often customized to the participants' interests and routine (e.g., making selections from a closed set of choices pertaining to their routine). Although FC did not progress to a conversational context, the set work activities continued to incorporate aspects of FC-like interventions, including intensive and extended interactions, focus on literacy skills, and age appropriate treatment during interactions. The facilitators involved in these interventions often reported that they felt they were actively guiding the participant when words were spelled within set work activities. Consequently, the answers to questions or structured choices made within the set work activities were not generally viewed by the facilitators as reliable communications of the participants alone nor as a reliable indication of the participants' skill levels. At times the generated answers or choices were responded to by facilitators as if communications of the participant, even though facilitator influence was viewed as likely. The typed output generated was of varying levels of intelligibility, often with only the first one to three letters being correct.

The facilitators often reported using strategies within the set work context to increase participants skills in areas such as literacy, motor control, attention to task or communication. In this way, the interventions maintained a training focus. For example, guiding the participant's hand to letter targets while spelling words was sometimes used and viewed as literacy training for the participant.

The focus on skill training for the participant was in contrast to the purpose of set work as described by the experienced FC practitioner. She stated that the main purpose of set work was to train the facilitator on how to successfully use FC with the participant.

Changes In Participants Coinciding With FC Use

Slight, and in many cases, inconsistent trends were noted in changes in behavior for of all but one participant. Behavioral changes that were noted during the course of the project often coincided with changes in routine, such as staff or job changes. Some of the

changes in routine were in response to using FC for communicating (e.g., many changes in routine occurred in response to facilitated allegations).

The noted changes in skill levels (e.g., communication skills) were in small and specific aspects of interaction or use of augmentative communication displays. Variability in performance was common. Some of the changes that were suggested by the data for three or more of the six participants completing the project included:

- increases in greeting and farewell behaviors within therapy sessions
- increases in initiations in using the communication display or pursuing the physical support from the facilitator during therapy sessions
- increases in eye contact with partners during therapy sessions
- increases in ratings of time on task during therapy sessions
- improvement in independent extension of the index finger for pointing tasks
- anecdotal reports and observations suggest that following the two initial sessions, people perceived that the client's skill levels were higher than previously believed.

One participant did demonstrate notable gains in several areas. The facilitators working with this individual (with the exception of the experienced FC practitioner within the introductory sessions) used the interventions within a structured, set work context for the entire project. These gains included an increase in the quantity and quality of her spontaneous verbalizations, increases in her eye contact with others, and increases in independence in spelling single words on a typewriter (without facilitation). Her records at the onset of the project indicated that she had a small core of spoken words and one to three word phrases that were often of poor intelligibility. She was described as not often initiating conversation. Her increases in speech were noted anecdotally by residential and vocational service providers, within counts of verbalizations done regularly at her work site, and within comparison of 40 minute videotaped pre and post assessment sessions (rising from a count of 45 to 192 verbalizations). The counts and anecdotal reports also indicated that she was more frequently using longer phrases and sentences (three to four element phrases; one sentence within the post-assessment session included seven words.

This participant was known to have some literacy skills at the start of the project. However, she was not actively using literacy skills on a day to day basis. By the end of the project, she was frequently typing words of varying levels of intelligibility without facilitation. The language level of her independent written output was generally less sophisticated than the level of her spoken language, both before and during the intervention.

Conclusions

The results of this project suggest that the term FC refers to a multiple component intervention; consequently it was deemed unwise to draw global conclusions about the efficacy of FC without examining the specific processes or practices associated with it.

From this examination and the outcome results of this project, it appears that the key feature that primarily distinguishes FC from other interventions is the practice and necessity of interpreting the messages that are produced by the person with a communication impairment as fundamentally authored by that individual and reflective of their cognitive and communicative skill level. When FC used as valid communication

was separated from other "FC inspired" practices or techniques, two major conclusions were evident from the results of this study.

First, the practice of interpreting messages produced with the physical support of a facilitator as authentic client communications is associated with risks. These risks can overshadow and negate any potential benefits. These risks are directly related to the lack of proof that the facilitated messages are those of the clients rather than the facilitators.

Second, there are beneficial therapy and training practices and philosophies that could be extracted and used separate from FC in therapy and training programs (e.g., augmentative communication programs).

Risks Or Potential Negative Outcomes Associated With Use Of FC

This project has identified that the use of FC is associated with significant risks to the user, their service providers, and family.

- It appears likely that messages of unsubstantiated origin that address significant issues will at some point be facilitated (e.g., allegations of abuse; stating choices of school, job or living situations, choice of guardian).
- The uncertainty of message authorship combined with the impact of significant life decisions or statements can lead to serious and prolonged controversy. This has the potential to have a long term, negative effect on the individuals involved (users, facilitators, and others), as occurred in this project.
- This risk is presently intensified because of the perception that non-controversial methods of establishing user authorship of such messages are not available (i.e., many proponents of FC find fault with currently used validation practices).

Similar risks and outcomes have been reported around the country (e.g., Eberlin, McConnachie, Ibel, & Volpe, 1993; Moore, Donovan, Hudson, Dykstra, & Lawrence, 1993; Wheeler, Jacobson, Pagliere, & Schwartz, 1993). Until satisfactory methods of establishing the authorship of facilitated messages are available, the significant risks and potential for negative impacts associated with using FC as a method of communication will persist.

Based upon the results of this project, the risks involved in the use of FC (which involves viewing facilitated messages as authentic client communications) overshadow any potential collateral benefits of FC (e.g., improvements in such areas as eye contact, initiations, speech).

Useful Practices Can Be Extracted From FC And Used Within Therapy And Training Programs To Achieve The Potential Benefits Without The Associated Risks

The individual who demonstrated the most substantial positive changes during the course of the project was not using FC as a method of valid communication within conversations. Her regular intervention consisted of the use of customized set work, with emphasis on literacy training, the regular use of known literacy skills, the use of touch to

maintain adaptive behavior, engaging in extended interpersonal interactions, and the provision of age appropriate regard. These observations support the notion that extracting the helpful practices and philosophies from FC, incorporating these practices into a skill development program., and labeling these practices by other terms may be beneficial.

This and other results from our project suggest that many of the collateral benefits of FC could be achieved through intervention programs that use some of the specific techniques associated with FC but that does not involve the presumption of client authorship of facilitated messages.

Recommendations

1. The project identified a number of practices and philosophies that could be extracted from FC and used in non-FC therapy and training programs (e.g., augmentative communication and assistive technology strategies. It is recommended that the following practices and philosophies be considered for active implementation within skill development and service delivery programs for individuals who have a severe communication impairment:

    - age appropriate regard
    - use of touch strategically to enhance skill development or adaptive behavior
    - participation in extended interpersonal interactions
    - pursuit of a more positive regard and value of individuals who have severe communication impairments
    - setting a time and place for reconsidering a person's skills and potentials
    - extensive exploration of literacy skills and potentials
    - creating opportunities for adults with disabilities to use their known literacy in their daily lives

2. If practices or philosophies, such as those mentioned above, are lifted from the context of FC into a skill development program, they should be referred to by their descriptive name (e.g., age appropriate regard, literacy exploration, interaction training). A descriptive terminology will prevent potential confusion between these "FC inspired" training practices and philosophies and FC. For example, part of the implementation of an augmentative communication board might include the strategic use of touch to improve the user's ability to maintain the appropriate hand shape for pointing. If selections of letters or pictures are made in the context of this training they would not be viewed as valid communications of the user. The purpose of the physical support would be for improving pointing skills.

3. It is mandatory that service providers and families continue to search for ways to help this population communicate more effectively. It has long been apparent that many individuals who have a severe communication impairment have not developed an effective means of communication through traditional augmentative communication approaches. Efforts to develop an effective means of communication have often been hampered by factors including:

    - a lack of access to appropriate augmentative communication services and technology

- the user's inability to spell to generate the vocabulary they need, as they need it (in some cases resulting from inappropriate or limited literacy training)

- limited opportunities to learn and participate resulting from inappropriately low expectations from others

- the lack of opportunities to communicate and participate in extended interactions with others

Extracting helpful practices and philosophies from FC might be one way to address some of the obstacles confronted in achieving effective communication for this population. Exploring other new technologies, such as voice output technology, might also be worthwhile for some people. For example, digitized voice output devices have become available that are less complicated, less expensive, and more portable than before.

4. The Trace Center recommends that–

   a. There must be objective evidence that the messages, produced in conjunction with FC, are solely authored by the individual with the communication disorder before FC is used:

      - As a method for evaluating or inferring skills (e.g., within cognitive testing)

      - As a method of communicating important decisions

      Message authorship should be established within objective procedures which control for the influence of the facilitator in producing messages.

      The results of this project along with results of numerous research studies around the country support this recommendation.

   b. That potentially useful practices and philosophies be extracted from FC for further exploration within skill development and service delivery programs for individuals who have severe communication impairments.

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Appendix A

Description of Behavior Tracking

Through observation, video, and consultation with family members and service providers, project staff selected behaviors specific to each client to be tracked during the project. The number following each behavior indicates the number of clients for whom that behavior was tracked. The behaviors tracked before and during the project included:

Adaptive behavior such as:

- Social or Activity Initiations (4)
- Mood (6)
- Focus on task (4)
- Smile (1)
- Social interaction (5)
- Verbalizations (2)

Low level challenging behavior such as:

- Stalling or perseveration (3)
- Impulsivity (1)
- Touching (3)
- Preservation 1
- Threatening gestures
- Yelling (2)
- Negative statements (3)

High level challenging behavior such as:

- Self injury (3)
- Screams (3)
- Aggression (5)
- Destruction (1)
- Rages (1)
- Hand biting (2)
- Head banging (1)

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Appendix B

Description of FC Checklist Used

A checklist was designed by project staff as a tool to systematically and efficiently collect information during therapy sessions. Its design was based on a consultation summary checklist designed and used by the Adriana Foundation in Massachusetts. It was to be completed, ideally by each facilitator, after every session using FC. The purpose of the checklist was to systematically collect information concerning components of the intervention and track changes in how the components were used over time (e.g., tracking the use of resistance by each facilitator over time). In addition, it was the aim to record information pertaining to the strategy being used in applying the FC technique. And finally, the checklist was a method of recording small changes that occurred in relation to the client's performance in the area of general communication (e.g., making eye contact with their partners), use of an augmentative communication aide, and specific aspects of behavior (e.g., time on task).

The following areas were included on the checklist. Information is provided on how this area was tracked on the checklist.

Support:

Support (or how firmly the facilitator grasped the client's hand) was rated on a 0-10 scale, with 0 being "light support", 5 being "moderate" support, and 10 being firm support. Brief definitions of these descriptions were explained to the facilitators and available on the data sheets. Light support was defined as light touch, moderate support was defined as similar to a handshake, and firm support was defined as deep pressure. The facilitator was asked to indicate ratings for the beginning, middle, and end of the session along the scale; however, in practice most of the facilitators provided one rating presumably representing an average of support for the whole session.

Resistance (pulling back):

Ratings of resistance were made on a 0-10 scale with 0 representing no resistance, 3-4 representing minimal resistance, 6-7 representing moderate resistance, and 10 representing maximum resistance. The following guidelines were used in making the ratings: no resistance given, minimal resistance = facilitator intermittently pulls back between keystrokes, moderate resistance = between each keystroke the facilitator pulls back, maximum resistance = between each keystroke the facilitator pulls back and holds. The facilitator was asked to indicate ratings for the beginning, middle, and end of the session along the scale; In practice most of the facilitators provided one rating presumably representing an average of resistance for the whole session.

Guidance (facilitator directing client's movement toward selection):

Guidance was rated on a scale from 0-10, 0 being support only and 10 being total guidance. On the instructions to the rater, guidance was defined as the facilitator directing the client's movement toward the selection. The rater was asked to indicate perceived levels of guidance for the beginning, middle, and end of the session. In general, raters provided only one rating, presumably an average of guidance for the whole session.

Eye Contact on Display:

Facilitators were asked to rate the amount of time the client attended to the communication display as appropriate. This area was defined as the amount of time the

client spent looking at the display during the typing task. A 0-10 scale was used with 0 being no eye contact on the display, 5 being 50% eye contact on the display when appropriate, and 10 being 100% appropriate eye contact with the communication display.

Eye Contact with Partner:

The rater of eye contact with partner was asked to answer the question "how much did the communicator look at the facilitator when they conversed between typing tasks" by their ratings. Eye contact with communication partners was rated on a 0-10 scale, with 0 representing no eye contact with partner, 5 representing 50% appropriate eye contact with partner, and 10 representing 100% eye contact with partner.

Time on Task:

Time on task was defined on the FC checklist as the amount of time the client attended to the typing task when it was appropriate. A 0-10 scale was used, with 0 indicating no time on task and 10 indicating that the client was on task for the entire session.

Initiation:

Specific aspects of each client's initiation behavior as it related to using augmentative communication equipment and facilitated communication was observed during each FC session. Specific aspects of using communication equipment were observed including approaching the communication equipment, positioning the communication equipment, positioning self to begin communicating, and producing an extended index finger for pointing. Following verbal requests to begin communicating and giving a signal of readiness to indicate intention to communicate were also noted. Items observed related to using touch within the context of FC and included initiating the physical support of the facilitator and initiating changes in the manner of facilitation used. These items were identified as small, subtle, and yet important components that are a part of communicating using an augmentative communication system and FC. Tracking these fine components of using an augmentative communication system would be sensitive to very subtle changes that might occur for someone using the intervention. The subtle components of using an augmentative communication system and FC to access it also might be considered an indication of the client's level of engagement in the interaction. Some of the components of using FC were also identified in personal consultation with the expert facilitator (March 18, 1993). She report initiations that she had observed while communicating with individuals who were using FC to access communication equipment, particularly experienced FC users.

Communication Setup:

This section of the checklist had to do with recording the client's behavior as it related to the communication set up. This included noting if any resistance was present in cooperating with the position of the facilitator, other communication partners, or with the touch of the facilitator. It was also noted whether equipment was left in the proper position for communicating. And finally, the client's behavior toward the communication equipment was noted and recording if inappropriate behavior was presented toward the equipment. These subtle areas of using an augmentative communication system or facilitated communication to access the equipment must be in place if the client is to successfully participate in using the equipment using FC support, therefore it was felt relevant in tracking behavior that might potentially change during the course of FC intervention.

Appendix C

Quotes From Initial Sessions

"I want to rememcer thiss moment forever"

"HOW SAD THAT IM SMART IN A STUPID BODY"

"i am frequently baffled by my body"

"my mom is great to me i love her"

"I THINK YOU HAVE CHANGED MY LIFE. THANK YOU"

"WILL YOU TEACH OTHERS TO HELP ME"

"i ewill be empathetic to their lerkning"

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